

# Temporal Trends in Recording of Diabetes on Death Certificates

## Results from Translating Research Into Action for Diabetes (TRIAD)

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**OBJECTIVE**—To determine the frequency that diabetes is reported on death certificates of decedents with known diabetes and describe trends in reporting over 8 years.

**RESEARCH DESIGN AND METHODS**—Data were obtained from 11,927 participants with diabetes who were enrolled in Translating Research into Action for Diabetes, a multicenter prospective observational study of diabetes care in managed care. Data on decedents ( $N = 2,261$ ) were obtained from the National Death Index from 1 January 2000 through 31 December 2007. The primary dependent variables were the presence of the ICD-10 codes for diabetes listed anywhere on the death certificate or as the underlying cause of death.

**RESULTS**—Diabetes was recorded on 41% of death certificates and as the underlying cause of death for 13% of decedents with diabetes. Diabetes was significantly more likely to be reported on the death certificate of decedents dying of cardiovascular disease than all other causes. There was a statistically significant trend of increased reporting of diabetes as the underlying cause of death over time ( $P < 0.001$ ), which persisted after controlling for duration of diabetes at death. The increase in reporting of diabetes as the underlying cause of death was associated with a decrease in the reporting of cardiovascular disease as the underlying cause of death ( $P < 0.001$ ).

**CONCLUSIONS**—Death certificates continue to underestimate the prevalence of diabetes among decedents. The increase in reporting of diabetes as the underlying cause of death over the past 8 years will likely impact estimates of the burden of diabetes in the U.S.

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In 2005, the National Center for Health Statistics ranked diabetes as the fifth leading cause of death in the U.S (1). Although it is difficult to determine the true extent to which diabetes should be recorded as a cause of death, this is likely an underestimate since diabetes is listed anywhere on the death certificate of fewer than half of people with known diabetes who die (2–5). Although using mortality data for epidemiologic studies is a common practice, it has drawbacks. When one studies mortality rates over time

using death certificates one generally assumes that the likelihood of recording the condition remains constant over time, so that observed changes in mortality reflect true changes in the rate and not simply changes in recording practices. The last national study investigating trends in reporting of diabetes on death certificates used the 1986 and 1993 National Mortality Follow-back Survey and documented consistent underreporting over time (2). One smaller, more recent study looking at the sensitivity and specificity of reporting

of diabetes on death certificates reported similar results (4).

We hypothesize that diabetes reporting on death certificates may have improved since 2000 because of the increasing prevalence of diabetes and the increased media attention to diabetes. The objective of this study was to determine the frequency of reporting of diabetes on death certificates of decedents with known diabetes and to describe trends over 8 years using data from Translating Research into Action for Diabetes (TRIAD). TRIAD was ideal for this study because it involved a racially and ethnically diverse sample of adults with diabetes from six sites across the United States and because all participants had been diagnosed with diabetes for at least 1 year before enrollment.

## RESEARCH DESIGN AND METHODS

### Study population

TRIAD has been described in detail elsewhere (6). In brief, TRIAD studied a random sample of adults with diabetes from 10 health plans and 68 provider groups serving approximately 180,000 patients with diabetes. Patients were eligible to participate if they were at least 18 years old, lived in the community, were not pregnant, had diabetes for at least 1 year, spoke either English or Spanish, were continuously enrolled in the health plan for at least 18 months, used at least 1 service during that time, and could give informed consent. Institutional review boards at each participating site approved the study.

In 2000 and 2001, we administered a survey either by computer-assisted telephone interview or in writing by mail. Centrally trained reviewers reviewed medical records for each participant using standardized data collection methods to abstract process of care measures, clinical parameters, and laboratory values. Each year, we obtained information on TRIAD decedents using National Death Index (NDI) Plus searches (7). All deaths were verified by matching name, social security

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number (available for ~52% of participants), date of birth, and sex of the decedent with data supplied by the NDI. The sensitivity of NDI has been shown to range from 87 to 98% (8). Different combinations of identifiers excluding social security number correctly identify 83–92% of decedents and 92–99% of living individuals, making NDI an accurate source of ascertaining vital status even without social security number (9).

Vital status was determined for all TRIAD participants ( $n = 11,927$ ) through 31 December 2007. All information regarding ICD-10 codes for the underlying and contributing causes of death were derived from the NDI file. For our analyses, we included all TRIAD participants ( $n = 11,927$ ), 2,261 (19%) of whom were identified through NDI as having died before 1 January 2008. We excluded 2 decedents who had “N/A” listed as their underlying cause of death to yield a final study population of 2,259.

### Outcome measures and covariates

We used the underlying cause of death ICD-10 code on the NDI file to group causes of death. We investigated two dichotomous dependent variables: the presence of diabetes as defined by ICD-10 codes E10–E14 on the death certificates as either the underlying cause of death (disease or injury that initiated events resulting in death) or as a cause appearing anywhere on the death certificate (listed in Part I as a disease, injury, or complication that caused the death or in Part II as another significant condition contributing to death but not resulting in the underlying cause given in Part I). Covariates included age at death and duration of diabetes at death.

### Statistical analysis

We described the proportion of decedents with diabetes coded as the underlying cause of death or anywhere on the death certificate and then stratified by year of death and also diabetes duration at time of death. We tested for trends over time using the Cochran-Armitage (C-A) test for proportions. To adjust for age and duration of diabetes separately, we used direct adjustment for age and then duration of diabetes at death by applying the rates from 2007 to the population from 2002 to obtain adjusted numbers to use for comparison purposes. We described the distribution of underlying cause of death stratified by year of death using the following categories: diabetes (E10–E14),

cardiovascular disease (I00–I99), cancer (C00–C97), renal failure (N17–N19), infection (A00–B99, J10–J18), external (injury-related) causes (V00–V89), and all other codes. We again tested for trends over time using the C-A test for proportions. Finally, we described the distribution of underlying causes of death (combining data from 2000 to 2007) and, using cardiovascular as the reference group, listed the odds ratios and 95% confidence intervals for the odds of having diabetes recorded anywhere on the death certificate.

**RESULTS**—Forty-one percent of decedents had diabetes recorded anywhere on their death certificates, and 13% had diabetes recorded as the underlying cause of death. When we stratified by year of death (excluding year 2000 because of the small sample size,  $n = 11$ ), there was a significant trend for increased recording of diabetes as an underlying cause of death over time (C-A trend test  $P$  value  $< 0.001$ ). We did not observe such a trend for recording of diabetes anywhere on the death certificate (C-A trend test  $P$  value = 0.10; Fig. 1A). Because duration of diabetes is a risk factor for recording of diabetes on death certificates (5) and because this was a cohort study in which duration of diabetes increased over time, we repeated the analysis after stratifying by diabetes duration at time of death (Fig. 1B). We observed an increase in the proportion of decedents with diabetes recorded on their death certificates in the groups with longer durations of diabetes and a statistically significant trend of increased recording of diabetes as the underlying cause of death by year of death for the longest duration group. The C-A trend test  $P$  value was 0.11 for the 5 to 14 year duration at death group and  $P = 0.01$  for 15+ year duration at death group. Although we did observe a higher proportion of reporting diabetes anywhere on the death certificate for the two groups with longer duration of diabetes, we did not observe a trend by year of death after stratifying by duration group ( $P = 0.80$  for 5 to 14 years and  $P = 0.46$  for 15+ years).

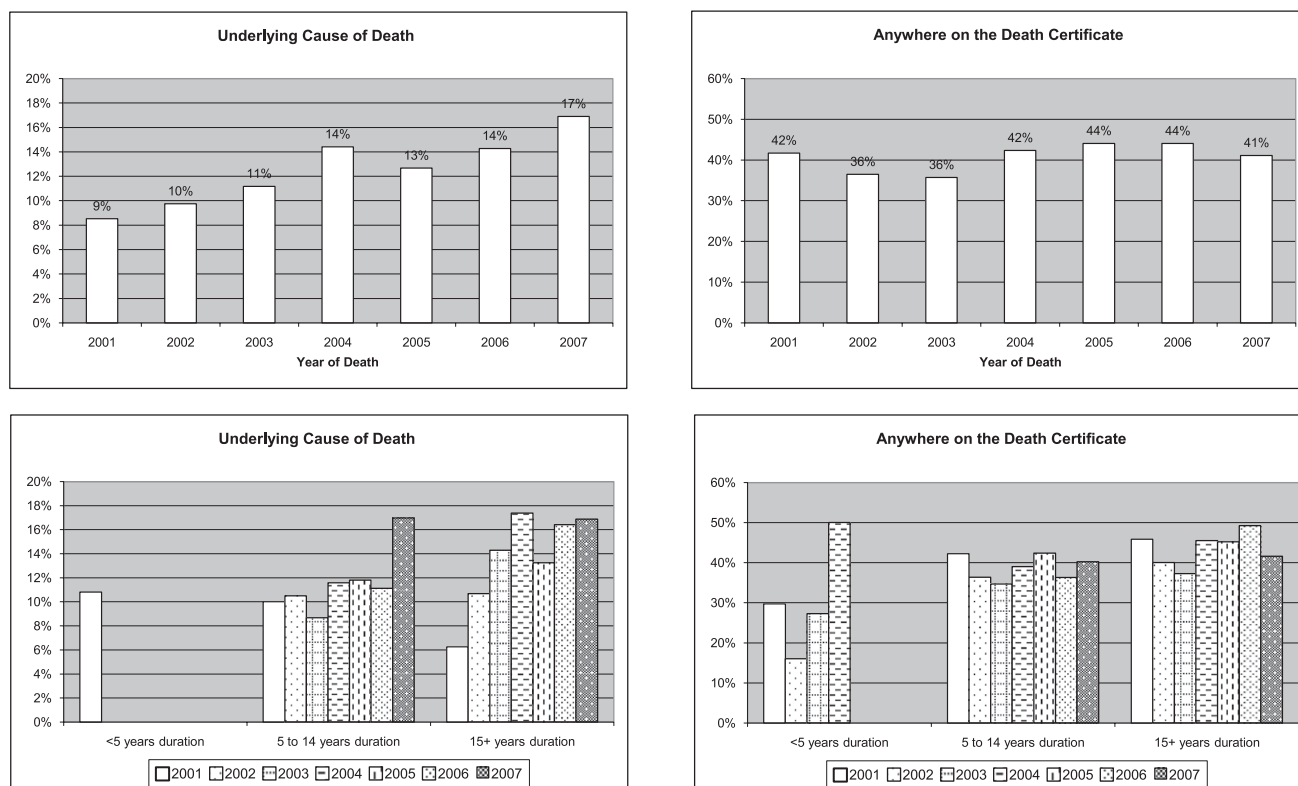
To adjust for differences in age at death, we then used direct age adjustment to apply the 2007 rate of recording of diabetes as the underlying cause to the 2002 standard number of decedents in 5-year age-groups from ages 30 to 95 and calculated an adjusted rate of recording of diabetes. The adjusted rate was 17.2% in 2007 compared with crude rates of 9.7% in 2002 and 16.9% in 2007. When we

used direct adjustment for duration of diabetes at death using 5-year duration groups from 5 to 80 years and calculated an adjusted rate of recording of diabetes as the underlying cause of death, it was 15.2% in 2007. Thus, even after accounting for age at death or duration of diabetes at death, the rate of recording diabetes as the underlying cause of death was higher in 2007 than in 2002.

As the percent recording of diabetes as the underlying cause of death increased over time, the percent recording of other competing underlying causes of death had to decrease over time given only a single cause is indicated for each death (Fig. 2). We observed a statistically significant decrease in the reporting of cardiovascular disease as the underlying cause of death over time (C-A trend test  $P$  value  $< 0.001$ ), driven by a decrease in recording of cardiac causes of death for men (C-A trend test  $P$  value = 0.006) and cerebrovascular causes of death for women (C-A trend test  $P$  value = 0.01). Although there were only 72 deaths as a result of renal failure, there was also a statistically significant increase in recording of renal failure as the underlying cause of death over time (C-A trend test  $P$  value = 0.01); the latter was driven by increased recording in women (C-A trend test  $P$  value = 0.01) but not in men (C-A trend test  $P$  value = 0.21).

Table 1 shows the distribution of underlying causes of death and the odds of recording diabetes anywhere on the death certificate by underlying cause of death. Diabetes was less frequently coreported with all other underlying causes of death when compared with cardiovascular disease. This was statistically significant for all categories except for “influenza and pneumonia.”

**CONCLUSIONS**—In TRIAD, diabetes was recorded anywhere on the death certificate for 41% of decedents and as the underlying cause of death for 13% of decedents. Although we did not observe a change over time of the percent recording diabetes anywhere on the death certificate, we did observe a statistically significant trend of increased reporting of diabetes as the underlying cause of death over time, which persisted after adjusting for duration of diabetes at death and age at death. Because of competing causes of death, we also observed a decrease in the reporting of cardiovascular disease as the underlying cause of death. Diabetes was significantly more likely to be reported on the death certificates of decedents with



**Figure 1**—Top panels: Percent recording of diabetes as the underlying cause of death and anywhere on the death certificate by year of death, 2001–2007. Bottom panels: Percent recording of diabetes as the underlying cause of death and anywhere on the death certificate stratified by year of death and duration of diabetes at death, 2001–2007.

diabetes dying of cardiovascular disease than all other causes.

Our study, which found no change in the reporting of diabetes as a cause of death listed anywhere on the death certificate over time, is consistent with previous studies. Evans et al. (10) found there was no evidence of any improvement in reporting of diabetes anywhere on the death certificate over the past two decades (1994–2005) in Scotland. Similarly, Cheng et al. (4) found no trend over time in the reporting of diabetes anywhere on the death certificates by decade from 1972 to 2003 in the Ranch Bernardo California cohort. Thomason et al. (3) observed a nonsignificant increase in reporting of diabetes anywhere on death certificates in the UK Prospective Diabetes Study cohort when they compared 1985–92 (41%) to 1993–99 (44%), but when they examined reporting of diabetes stratified by age, sex, and date of death, they found a few changes that were limited to people 65+. Specifically, men who died of cardiovascular disease were more likely to have diabetes reported in 1993–99 than 1985–92, and men who died of other causes were less likely to have diabetes reported in 1993–99 than 1985–92 (3).

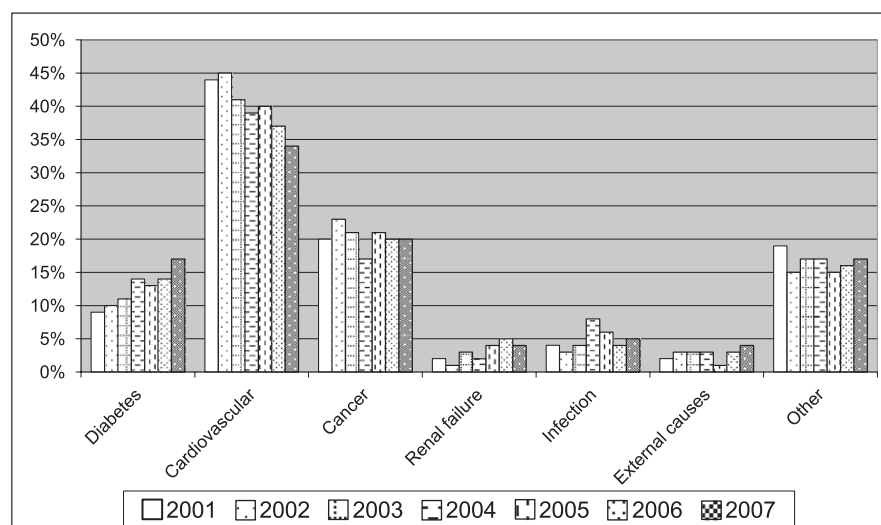
These studies did not investigate trends in reporting diabetes as the underlying cause of death over time. Although we are not the first to investigate temporal trends in recording of diabetes as the underlying cause of death on death certificates (2–4,10), we are the first to report a change in recording over time in the proportion of decedents with known diabetes having diabetes reported as the underlying cause of death. Will et al. (2), who analyzed U.S. data from 1986 and 1993, found no difference in the percent reporting diabetes as the underlying cause of death over time. They only compared 2 points in time 6 years apart, whereas our study looked at 8 consecutive years of more recent deaths. We observed a significant increase, with the largest increase in reporting in the most recent year, 2007. None of the previous studies, even those that analyzed diabetes anywhere on the death certificate, has had data available past 2005. In addition, Cheng only looked at trends by decade, whereas we looked at trends by year, so we may have been able to detect smaller differences.

If confirmed, our results have important implications on the interpretation of

mortality trends in people with diabetes. For example, Wier and Gjelsvik (11) showed a decrease in mortality from 1995 to 2005 in Rhode Island when they identified people with diabetes using the underlying cause of death on death certificates. This slight decrease may underestimate the true decrease if recording increased over time, from 2000 to 2007, as suggested by our study.

We found that diabetes is most frequently coreported with cardiovascular causes of death, a finding similar to a previous study that showed that diabetes was more likely to be reported on death certificates of people dying of cardiovascular causes compared with all other causes (4). This is also consistent with results from Thomason et al. (3) who showed that reporting of diabetes was more frequent when cardiovascular disease was the underlying cause of death (46%) versus all other causes (39%).

A limitation of our study is that we only studied people enrolled in managed care health plans. Our population may have had better access to care and better risk factor control, especially for cardiovascular disease. This could explain why less than 50% of our population had cardiovascular



**Figure 2**—Distribution of underlying cause of death by year of death, 2001–2007.

causes listed as the underlying cause of death. Our findings may not be generalizable to other populations. Our study was geographically, ethnically, and racially diverse, collected patient level data before death, and did not solely rely on death certificates.

There are many problems related to the reliability and validity of cause-of-death information on death certificates of people with diabetes. These problems relate to the lack of training in death certificate completion, inaccuracy of diagnosis, changing

perceptions of the causal role of diseases, improper completing of death certificates, and variation in interpreting causal sequences leading to death (12–16). Reporting of cause of death can be especially problematic when a decedent has multiple chronic conditions including diabetes, because a single disease may not adequately describe the cause of death, and, clearly, not everyone with diabetes dies from diabetes. This being said, death certificates are commonly used to rank causes of death, to describe trends in mortality over time, and to define

the burden of disease in populations (1,11,17). Although diabetes listed as any cause of death was stable over time, we have observed a statistically significant increase in reporting of diabetes as the underlying cause of death on death certificates between 2001 and 2008 independent of age at death and duration of diabetes at death. If this trend is indeed occurring on a national level, it may complicate the interpretation of mortality rates ascertained from death certificates.

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L.N.M. researched data, contributed to discussion, wrote the manuscript, and reviewed and edited the manuscript. A.J.K., J.D.C., D.G.M., J.C.C., and W.H.H. contributed to the discussion and reviewed and edited the manuscript.

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**Table 1**—Distribution of underlying causes of death for TRIAD decedents (n = 2,259) and odds ratio (95%CI) of recording diabetes anywhere on the death certificate using cardiac causes as the reference group, 2000–2007

Underlying cause of death	ICD-10 codes	Percentage of deaths by underlying cause of death (%)	Odds ratio of having diabetes recorded anywhere	95% CI	
				Lower	Upper
Cardiovascular	I00–99 (except I60–69)	34	1.00	—	—
Cancer	C00–97	20	0.46*	0.35	0.59
Diabetes	E10–14	13	—	—	—
Other	All other	11	0.63*	0.46	0.85
Cerebrovascular disease	I60–69	5	0.63*	0.41	0.94
Respiratory	J00–09, J19–99	5	0.65*	0.43	0.98
Renal failure	N17–19	3	0.29*	0.15	0.55
Infections	A00–B99	3	0.59*	0.35	0.99
External (injury-related) causes	V00–Y89	3	0.45*	0.24	0.84
Influenza and pneumonia	J10–18	2	0.67	0.32	1.38

\*P ≤ 0.05.

## References

- Heron M, Tejada-Vera B. Deaths: leading causes for 2005. *Natl Vital Stat Rep* 2009; 58:1–97
- Will JC, Vinicor F, Stevenson J. Recording of diabetes on death certificates. Has it improved? *J Clin Epidemiol* 2001;54:239–244
- Thomason MJ, Biddulph JP, Cull CA, Holman RR. Reporting of diabetes on death certificates using data from the UK Prospective Diabetes Study. *Diabet Med* 2005;22:1031–1036
- Cheng WS, Wingard DL, Kritiz-Silverstein D, Barrett-Connor E. Sensitivity and specificity of death certificates for diabetes: as good as it gets? *Diabetes Care* 2008;31: 279–284
- McEwen LN, Kim C, Haan M, et al.; TRIAD Study Group. Diabetes reporting as a cause of death: results from the Translating Research Into Action for Diabetes (TRIAD) study. *Diabetes Care* 2006;29: 247–253
- TRIAD Study Group. The Translating Research Into Action for Diabetes (TRIAD) study: a multicenter study of diabetes in managed care. *Diabetes Care* 2002;25: 386–389

7. Centers for Disease Control and Prevention. National Center for Health Statistics: National Death Index (NDI), NDI Plus Searches. Available from <http://www.cdc.gov/nchs/ndi.htm>. Accessed 2 September 2010
8. Cowper DC, Kubal JD, Maynard C, Hynes DM. A primer and comparative review of major US mortality databases. *Ann Epidemiol* 2002;12:462–468
9. Williams BC, Demitrack LB, Fries BE. The accuracy of the National Death Index when personal identifiers other than Social Security number are used. *Am J Public Health* 1992;82:1145–1147
10. Evans JM, Barnett KN, McMurdo ME, Morris AD. Reporting of diabetes on death certificates of 1872 people with type 2 diabetes in Tayside, Scotland. *Eur J Public Health* 2008;18:201–203
11. Wier LM, Gjelsvik A. Diabetes mortality in Rhode Island: comparing underlying cause of death versus any listed cause of death. *Med Health R I* 2008;91:86–87
12. Geiss LS, Herman WH, Smith PJ. Mortality in non-insulin-dependent diabetes. In *Diabetes in America*. 2nd ed. Harris M, Cowie C, Stern M, Boyko E, Reiber G, Bennett P, Eds. Bethesda, MD, National Institute of Diabetes and Digestive and Kidney Disease, 1995, p. 233–258 (NIH publ. no. 95-1468)
13. Lu TH, Anderson RN, Kawachi I. Trends in frequency of reporting improper diabetes-related cause-of-death statements on death certificates, 1985–2005: an algorithm to identify incorrect causal sequences. *Am J Epidemiol* 2010;171:1069–1078
14. Lu TH, Hsu PY, Bjorkenstam C, Anderson RN. Certifying diabetes-related cause-of-death: a comparison of inappropriate certification statements in Sweden, Taiwan and the USA. *Diabetologia* 2006;49:2878–2881
15. Lu TH, Walker S, Johansson LA, Huang CN. An international comparison study indicated physicians' habits in reporting diabetes in part I of death certificate affected reported national diabetes mortality. *J Clin Epidemiol* 2005;58:1150–1157
16. Tierney EF, Geiss LS, Engelgau MM, et al. Population-based estimates of mortality associated with diabetes: use of a death certificate check box in North Dakota. *Am J Public Health* 2001;91:84–92
17. Gross CP, Anderson GF, Powe NR. The relation between funding by the National Institutes of Health and the burden of disease. *N Engl J Med* 1999;340:1881–1887